the nimh community support program: pilot approach to a needed social reform*

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This year, the National Institute of Mental Health (NIMH) launched a modest but potentially significant pilot program titled the Community Support Program (CSP). CSP is designed to improve services for one particularly vulnerable population—adult psychiatric patients whose disabilities are severe and persistent but for whom long-term skilled or semi-skilled nursing care is inappropriate.

Specifically, CSP involves contracts (not grants) between NIMH and State mental health agencies, many of whom will subcontract with local agencies for demonstration projects. To date, 19 States have been awarded CSP contracts amounting to a total of approximately $3.5 million for the first year's activities.

Although the program is so new that little has been published about it, interpretations are beginning to appear in the press and the professional literature. The *New York Times* (February 7, 1978), for example, while emphasizing the need for Federal leadership to improve services to chronic patients, referred to the CSP initiative in an editorial as "belatedly pulled together" and "meager."

Professional literature has viewed it more positively. A recent article in the *Scientific American* (Bassuk and Gerson 1978, p. 53), for example, highlighted the importance of the program in "the acknowledgment of the specific needs of the chronic severely disabled person," and "the willingness of the Federal government to accept more responsibility for the mentally ill." The *APA Monitor* (Herbert 1977, p. 4) noted that "although fiscally undramatic, CSP nevertheless marks a major departure. The program's explicit message is that the mental health field is ready to assume leadership responsibility for securing not only mental health services, but also support and rehabilitation services in the community."

We regard this article as an opportunity to describe key features of the program and to present our interpretation of ways in which CSP holds promise as an approach to a complex service system problem. Our comments will be offered from the standpoint of two NIMH staff members who have been intimately involved in the program's design and who now have a stake in its success.[1] From this vantage point, we can more extensively discuss the ideas and perceptions that have shaped the program than is possible with official policy statements (Brown 1977; Califano 1977; Turner, Stone, and Ten Hoor 1977).[2] Our purpose is to present the rationale for decisions reached so far, and to invite comment related to important factors that may have been overlooked.

Program Focus: A Population Caught in a Systems Transition

A key feature of CSP is its focus on meeting

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[1]Judith Turner joined NIMH in 1974 as a Special Assistant to the Director of the Division of Mental Health Service Programs, focusing on the needs of the severely mentally disabled adult. William TenHoor jointed NIMH in 1976 to work with Ms. Turner on the same set of issues.

[2]See Community Support Section Request for Proposal No. NIMH-MH-0080 1977 and Request for Proposal No. NIMH-MH-0081 1977. See also Secretary Califano's press release, DHEW, November 1977.

the comprehensive needs of a well-defined population. CSP contracts are directed solely toward "severely mentally disabled adults whose primary disability is emotional and for whom long-term 24-hour nursing care is inappropriate" (NIMH CSP Guidelines 1977). Elderly persons are included in the population if they meet the above criteria, but excluded if they have physical or mental conditions requiring skilled or semiskilled nursing care.

Although systematic information on the size and current living conditions of the target CSP population is not readily available—particularly concerning the large numbers now residing outside hospital settings—independent estimates by three different sources suggest that the total number of persons nationwide who fall within this definition is more than 1.5 million.[3]

The adult mentally disabled have been vulnerable throughout history to a variety of forms of exclusion, neglect, and even abuse. The literature of the past few years reflects increasing concern from diverse perspectives that services to this population are in a state of crisis. Whereas reform efforts of the 1950s and 1960s emphasized the inhumane conditions in large mental hospitals, in the current decade attention has shifted to problems connected with "community placement" of the same population.

Journalistic Accounts

Current media accounts of discharged patients in communities without adequate services reflect two broad themes: concern for the safety and well-being of patients themselves, and fear or resistance of the general citizenry toward mentally disabled persons in their midst. An example is a report commissioned by a union representing State hospital employees and published under the title *Out of Their Beds and Into the Streets* (Santiestevan 1975). This report asks "how to explain a national *non*policy on mental health that releases mental patients into community facilities that don't exist and protects their right to treatment by denying them publicly provided health services." It is argued further that " 'deinstitutionalization,' a lofty idea, has become something very ugly—a cold methodology by which government washes its hands of direct responsibility for the well-being of its most dependent citizens."

Professional Criticism

Professional literature of the early 1970s expresses similar concern, highlighting numerous deficiencies in existing community care systems. A theme in much literature of the period is the failure of the community mental health movement to bring significant benefits to the severely mentally ill (Arnhoff 1975; Kirk and Therrien 1975; Reich and Siegel 1973).

Klerman (1977) refers to these patients as "better but not well," and mentions their need for "some degree of social support—e.g., welfare or disability payments, special residential placements, and social and recreational supervision, usually in day programs" (p. 628). Speaking of "the dilemmas of partial success" in the deinstitutionalization process, he suggests that the mental health movement may have become overambitious in the late 1960s, expanding its responsibilities too broadly, "before being sure that the need to solve the problems of schizophrenics—one of our primary clinical obligations—had been fulfilled" (Klerman 1977, p. 626).

Kirk and Therrien (1975) identify four myths that they believe have obscured the fate of former patients. While community mental health ideology was based on beliefs that community care would save money, that continuity of care would be enhanced, that former patients would be rehabilitated, and that the mentally ill would be reintegrated into society, these hopes have not been fulfilled. Victims of the gap between rhetoric and reality have been the more disabled patients diverted or discharged from public mental hospitals and those remaining hospitalized for lack of appropriate alternatives.

The myth of rehabilitation is an underlying theme in Kohen and Paul's (1976) review of

[3]These estimates were provided by NIMH's Division of Biometry and Epidemiology (Taube 1977), and by Bradley (1976) and Minkoff (1978).

proprietary extended care facilities for the chronically mentally ill. They point out that the "aggressive placement of long-stay mental patients in [such] facilities—for example, foster homes, nursing homes, shelter-care homes, or other board-and-care facilities—accounts for nearly all of the reductions in the chronic population. . ." (p. 576) of public hospitals over the past 15 years. While professional followups of these placements have been relatively scarce, Kohen and Paul (1976) cite several studies supporting their thesis that extended-care placements have improved neither rehabilitation programming nor the functional status of chronic mental patients (Ellsworth 1968; Epstein and Simon 1968; Hefferin 1968; Lamb and Goertzel 1972; McClannahan and Risley 1975).

The myth of reintegration is addressed by Aviram and Segal (1973) who discuss new forms of social exclusion of the mentally ill in the community. "In many cases where the mentally ill are in the community," they state, "they are socially excluded by mechanisms that foster a docility (such as overuse of drugs and the caretaker's economic incentive to maintain a stable resident population rather than to encourage a higher level of functioning) or by forces that encourage ghettoization (such as zoning laws and local administrative regulations)" (p. 131).

Arnhoff's (1975) review of social policy toward mental illness raises an even more fundamental question. "A compelling body of systematic evidence now exists to suggest that the actual cost-benefits of community-treatment (using cost in its broadest sense) are far less than its advocates proclaim, but that the consequences of indiscriminate community treatment may often have profound iatrogenic effects: in short, we may be producing more psychological and social disturbance than we correct" (p. 1,277). In light of this possibility, he calls for abandoning "the individual patient model in favor of a more extensive, complicated (and costly) system model" (p. 1,277). One implication of this recommendation is the need to study how alternative treatment approaches affect not only the patients, but also their children, other family members, and the community.

A Consumer Perspective

Speaking from a consumer point of view, Allen (1974) attacks another myth associated with current services to the seriously mentally ill: the myth that hospital care is "bad" and community care is "good," or vice versa. She advocates improvements in *both* settings, particularly as they relate to the chronically disabled. Her critique of board-and-care homes in California, based on experience as a resident and a visitor, raises serious concerns about the quality of life in these settings. She cites deficiencies in meeting some of the most *fundamental* of human needs (e.g., nutritious and palatable food, personal safety, cleanliness, and adequate space). She reports that "There are more people around me [in board-and-care homes] who are hallucinating. . . and being tormented by these experiences . . . than there ever were when I resided in a large dormitory in a State mental hospital. . .. It troubles me to see them go on suffering day after day with apparently nothing being done about it" (Allen 1974, p. 5).

Her article is equally eloquent in describing the intangibles in such community facilities. She states that " 'treatment in the community' may actually mean *less real participation* than a person would enjoy 'confined' within an out-of-the-community state hospital (Allen 1974, p. 4). She goes on to say that "the pervasive atmosphere within most board and care homes, rather than being one of outgoing, homey warmth, is that of cautious, cool silence. Residents seem fearful—reluctant to speak; to express themselves; or, when necessary, to protest" (Allen 1974, p. 10).[4]

Congressional Concern

The problems expressed by Ms. Allen from a consumer perspective are documented from a

[4]Priscilla Allen's concern about basic human and civil rights of former patients is developed in a later publication, "A Bill of Rights for Citizens Using Outpatient Mental Health Services" (Allen 1976). Her insightful and balanced analysis of problems led NIMH to engage her as a consultant in developing the Community Support Program, and her contributions have been invaluable.

Federal viewpoint by two recently published Congressional studies. A March 1976 Senate Subcommittee Report deplores conditions in proprietary nursing and boarding homes, citing serious instances of neglect and abuse (Senate Subcommittee on Long-Term Care 1976). The report warns that privately operated boarding homes are like nursing homes, rapidly emerging as a major industry that will soon become intractable. The report also highlights problems connected with placement of ambulatory former mental patients in nursing homes designed for the physically disabled or dying.

Perhaps the most comprehensive study of the issues from a Federal perspective is the 1977 report issued by the General Accounting Office (GAO). After extensive studies of services affecting treatment of the mentally retarded and the mentally ill in five States, the GAO concludes that "deinstitutionalization" has been adopted as a national policy without adequate mechanisms to implement the idea effectively. Like the Senate reports, the GAO finds that thousands of patients in mental hospitals remain there principally because few alternatives exist, while additional thousands are being placed in community facilities and settings that may be as stultifying and disabling as mental institutions.

Both Congressional studies agree that failure at the national level to develop a coherent policy toward the seriously mentally disabled is a major contributing factor to the current crisis in services to this population.

Legal and Judicial Pressures

Even as disillusionment with existing conditions has intensified, so have legal and judicial pressures on the system. Involuntary commitment to mental hospitals has declined as States have enacted new laws establishing more stringent procedural protections. Numerous court cases have established important precedents in such areas as the right of potential involuntary patients to procedural safeguards (*Lessard* v. *Schmidt*, 349 F. Supp. 1078, E.D. Wis., 1972); the right to treatment (*Rouse* v. *Cameron*, 373 F. 2d 451, D.C. Cir., 1966, and *Wyatt* v. *Stickney*, 344 F. Supp. 373, M.D. Ala., 1972); the responsibility to use the least drastic form of care (*Lessard* v. *Schmidt*); the right of nondangerous individuals to freedom (*O'Connor* v. *Donaldson*, No. 74–8, 1975); and the right to treatment in the least restrictive alternative (*Dixon* v. *Weinberger*, 405 F. Supp. 974, D.C., 1975).

The Supreme Court decision in the Donaldson case is particularly relevant to the population focus of CSP. The court held that "A State cannot constitutionally confine without more a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends." Equally relevant to CSP is the Dixon case, pushing beyond the walls of the institution to fix accountability for a more systematic and less restrictive service structure. The court held the Department of Health, Education, and Welfare (DHEW), which administers St. Elizabeths Hospital in the District of Columbia, and the District of Columbia Department of Human Resources jointly responsible for developing less restrictive services for more than a thousand hospitalized patients not regarded as needing hospitalization.

Basic Issues in Developing Community Support Systems

During the period from 1975–1977, certain themes emerged about the major causes of inadequacies in existing service systems. Several such themes reappeared in different arenas with sufficient frequency to suggest the elements of a Federal initiative.

Inadequate Definition of Service System Goals

Both Congressional studies emphasize the lack of a coherent Federal policy regarding services to the mentally disabled, pointing out that Federal rhetoric and policies have encouraged the trend away from reliance on institutions for long-term care, but have failed to provide ef-

fective implementation strategies. Failures in implementation have been such that the desirability of deinstitutionalization is being increasingly questioned. Discussions of this issue at NIMH working conferences (see p. 327 for a more detailed description) produced a clear consensus that the term "deinstitutionalization" is no longer useful as a planning goal. Indeed, overreliance on this ambiguous and misleading concept in the past may have contributed substantially to some of the system problems now being widely acknowledged by the press, the professions, consumers of mental health services, and others.

This view was stated as Public Health Service (PHS) policy in official comments on the draft GAO report (PHS 1976). These comments cite numerous disadvantages associated with deinstitutionalization as a goal: the implicit emphasis on getting rid of something negative, rather than creating something positive; the additional negative connotations in States where the term is now associated with "dumping" mentally disabled persons into neighborhoods lacking adequate services; the overly simplistic dichotomy implied by the term, suggesting that institutional care is "bad" and community care is "good"; and the fallacy of assuming (as was often done in the early days of deinstitutionalization) that success could be measured by counting the number of institutions closed down or the reductions in resident populations of public mental institutions.[5] In view of these disadvantages, the PHS comments on the GAO report state that "in the future the term deinstitutionalization will be used by the PHS as a neutral term rather than as a goal. . .. It is possible for poorly planned placements in the community to be just as inappropriate as placements in large institutions." This recognition suggests a need for a Federal initiative to reconceptualize service system goals.

[5]In a recent report on the phasedown of Retreat State Hospital in Pennsylvania, the Human Services Research Institute expressed this concern somewhat differently. They pointed out that deinstitutionalization has included two goals: reducing the size of institutions, and improving services to the clients. These two goals in reality often conflict in the short term. Phasing down institutions is politically sensitive and is a process that may encounter substantial resistance. Improving services for the mentally disabled, on the other hand, while difficult, is a goal to which most could subscribe at least in principle. For numerous reasons, they recommended that in the future mental health planners in Pennsylvania keep administrative and programmatic goals separate (Human Services Research Institute 1978).

Fragmentation and Confusion of Responsibility

Perhaps the most critical factor contributing to inadequacies in community-based care is fragmentation and confusion of responsibility among the many Federal, State, and local agencies whose programs have an impact on services to the mentally disabled in the community. In the past, State mental health agencies had clear responsibility for organizing and financing long-term care of the seriously mentally disabled. In recent years, responsibilities have been shifting from the mental health system to the welfare system, from State to Federal and local funding, and from the public to the proprietary sector. Under these circumstances, it is possible for all concerned agencies to "pass the buck" with respect to care of those who might in an earlier era have spent a large part of their lives in a mental hospital.

At the Federal level, the GAO report points out that "the agency primarily concerned with the mentally ill—NIMH—(1) provides only a small portion of the funds needed and used for deinstitutionalization [and development of community support services]; (2) exerts only a limited influence and no authority over other agencies; and (3) does not have authority or responsibility for monitoring, evaluating, and enforcing standards and requirements under other programs serving the mentally disabled" (GAO Report 1977, p. 36). Similar circumstances exist at State and local levels. No one agency at any level has been clearly charged with responsibility for comprehensive assessments of mental health and community support needs of the mentally disabled, planning and implementing a system to assure that needs are met, and monitoring the quality of both institutional and community programs. Responsibilities for these

functions are fragmented across three layers of government and among many health, mental health, and human service agencies. Consequently, many of the people most seriously in need of services are likely to "fall through the cracks." This problem suggests the need for a Federal initiative to clarify responsibilities at all levels.

Lack of a Systematic Approach to Financing Community-Based Services

An equally serious problem is the lack of a systematic approach to financing community-based services. Although it had been hoped that dollars in institutions would ultimately follow the patients into the community, this hope has generally not been realized. Hospital savings have been much less than expected, due in part to inflation and the costs of maintaining and upgrading physical plants and staffing patterns to meet certification requirements (and in some cases court orders). Transferring institutional resources to the community, though possible, has proved difficult.

One aspect of the financing problem highlighted by the GAO study is the fact that "funding for community-based mental health services has not grown in relation to the transfer of patients to communities and to the need" (GAO 1977). GAO investigators found that some States were reluctant to initiate new CMHCs because of declining Federal funding for such programs and because of difficulties in obtaining third party reimbursements. The report suggested a need to reexamine the Federal role in financing mental health services to determine whether more stable and flexible methods might be developed.

The transfer of individuals from State-operated facilities to local communities has been affected by other financing problems as well. Startup monies for new community programs are scarce. Federal funding patterns for mental health, housing, and human services are a "crazy quilt" of conflicting jurisdictions, formulas, eligibility requirements, and exclusions. Few States have established viable fiscal incentives to encourage local communities and service providers to accept responsibility for serving former mental patients in a comprehensive way.

A related problem brought into focus by the GAO report is the inappropriate use of existing Federal resources for community-based services. The two largest Federal funding streams available for community placement are Supplemental Security Income (SSI) payments to disabled individuals and Medicaid vendor payments to operators of intermediate or skilled nursing facilities. These two programs have, in fact, provided a major fiscal incentive to States to transfer thousands of people out of State-operated and financed institutions into nursing or boarding homes.

The interactive effects of the Medicaid and SSI programs on placement of the mentally disabled are complicated, however. Because SSI is an income payment to the individual, it has in some instances led to placement of persons in substandard facilities without provision for support services. In addition, the GAO found that certain SSI restrictions (some of which were removed by legislation enacted in August and October 1976) have impeded the provision of halfway-house services by publicly operated CMHCs and have tended to create incentives toward overuse of nursing homes. Another financing problem not mentioned by the GAO, but identified in the professional literature and in NIMH conferences, is the existence of fiscal incentives to nursing and boarding home operators to keep their facilities filled with a stable, docile population (Aviram and Segal 1973; Lamb and Goertzel 1971).

Additional problems associated with financing community support systems are cited in a background paper prepared for the Conference on the Chronic Mental Patient sponsored by the American Psychiatric Association (Sharfstein, Turner, and Clark 1978). Among the issues raised are: (1) the need to develop mental health financing mechanisms to encourage use of the least restrictive setting and the least obtrusive means (as opposed to the current incentives in Medicare, for example, toward inpatient hospitalization); (2) the need to clarify financing of special living arrangements for the mentally

disabled, and to develop funding mechanisms that encourage a continuum offering varying types and degrees of supervision and support; (3) the need to clarify financing patterns for daytime rehabilitative and supportive programs that do not unnecessarily perpetuate the patient role; (4) the need to develop funding mechanisms for long-term rehabilitative and supportive work opportunities; and (5) the need to develop financing mechanisms that facilitate rather than impede coordination of services at all levels (Sharfstein, Turner, and Clark 1978).

These issues are complex, suggesting the need for a careful sorting process to determine which problems can be solved at the local level, which require organizational, legislative, or regulatory changes at the State level, and which need Federal attention. There is also a need to determine more precisely what types of additional Federal resources, if any, may be necessary to assure adequate community-based services for the seriously mentally disabled.

Lack of Commitment of "Mainstream" Agencies to Serving the Mentally Disabled

As mentally disabled persons are increasingly treated outside of hospitals, it is essential that these individuals have access to the general services and resources to which they are entitled or for which they may be eligible. The GAO report suggests, however, that too often this does not occur. Once a person has been labeled "mentally ill" (or "mentally retarded") there is often a tendency for general service providers to regard the person as the primary responsibility of the mental health or mental retardation system, and to expect these systems to provide and fund *all* the needed services in the community. This expectation exists for many reasons: lack of a clear mandate for "mainstream" agencies to serve the mentally ill; lack of defined and appropriate roles; lack of experience and program models; competition from other vulnerable populations for limited resources; inexperience in working with the mentally ill; and bureaucratic inertia, to name a few.

The GAO report states that 11 major Federal departments and agencies administer at least 135 programs affecting the mentally disabled. In particular the report calls for more attention to the needs of the mentally disabled from such programs as the State/Federal vocational rehabilitation program, the social services program (Title XX), selected programs of ACTION, the Department of Labor, and the Department of Housing and Urban Development (HUD). This policy direction was strongly endorsed at NIMH working conferences focused on community support (see p. 327). Both as a practical matter and as a matter of principle, conference participants urged the development of mechanisms to increase access by the mentally disabled to general benefits and services to which they are entitled and for which they may be eligible. This principle also was strongly advocated at the January 1978 Conference on the Chronic Mental Patient, sponsored by the American Psychiatric Association.

Lack of Effective Community Organization and Advocacy

Many recent advances in opportunities and services for various disadvantaged populations have resulted from advocacy efforts by concerned citizens, professionals, parents, friends, and—most importantly—by the disadvantaged advocating on their own behalf. To date, however, positive community pressure on behalf of adults with psychiatric disabilities has been slight. With a few exceptions, the mentally disabled have yet to organize as an effective interest group. Groups of parents of mental patients, where they exist, are less vocal and less well organized than comparable groups formed by parents of mentally retarded or physically disabled patients. Citizen and professional groups active in mental health generally have avoided grappling with the long-term problems of the mentally disabled, and have focused instead on issues that seem to offer more immediate rewards. CMHC advisory boards, for example, have tended to focus on broader purposes and goals of community mental health rather

than to serve as advocates for the needs of the seriously mentally disabled. Thus the root of the problems in community services for the mentally disabled may well be the lack of an organized and caring constituency to work for improvements at all levels. This suggests the need for a process to convene and nurture such a constituency—a coalition of concern—within each State and community.

The Need for Leadership

All of these problems, although difficult, are amenable to solution. What has been particularly lacking, however, is clarity about who should provide the necessary leadership at Federal, State, or local levels to move things forward. The need for such leadership has been a recurring theme. Although there are serious difficulties inherent in attempting to assure a full range of community-based services for the mentally disabled, it would seem incumbent on the mental health system to assume a leadership role—particularly during the present period of major systems transition. The need for such leadership at all levels has been a recurring theme.

NIMH's Response: A Participatory Planning Process

The magnitude of the need for improved community services and the necessity for a more systematic approach was first given official recognition within NIMH in early 1974 with the establishment of an ad hoc internal Community Support Work Group initiated by Lucy Ozarin. The group defined its task as "promoting an organized community-based system of facilities and services to increase the opportunity for mentally handicapped adults to remain in the community and function at optimal levels of independence" (Ozarin 1974). The development of an NIMH strategy for pursuing this goal, i.e., the CSP, has been a participatory process involving dozens of people within NIMH and a wide range of individual consultants and organizations throughout the country.

Internal Participation

Internally, the process began with bi-weekly meetings of the Community Support Work Group, whose membership rapidly expanded beyond the Division of Mental Health Service Programs to include interested persons from nearly all major components of the Institute,[6] two other Federal agencies, and the Office of the HEW Secretary. Judith Turner was recruited as fulltime staff director in late 1974, with William TenHoor joining the community support unit in April 1976.

As the need for a special initiative became increasingly apparent, Frank Ochberg, then Director of the Division of Mental Health Service Programs, established a Task Force to update the Hospital Improvement Program and the Hospital Staff Development Program.[7] This group, co-chaired by G. Bart Stone and William TenHoor, recommended a phaseout of existing programs and the redirection of resources into a new CSP. A CSP Draft Proposal (Turner, Stone, and TenHoor 1977) was widely circulated to the field in March 1977 for comment. Based on an overwhelmingly positive response to the proposal, Bertram S. Brown, then Director of NIMH, authorized its further development and implementation.

A CSP Implementation Group was established in June 1977 under the chairmanship of Steven

[6]Membership of the Work Group included: Lucy Ozarin, M.D., Chairperson; Herbert Butler, Ed.D., Co-Chairperson; Judith Turner, Executive Secretary; Leona Bachrach, Ph.D; Morton Albert, M.D.; Toyo Biddle; John Biedenkapp; Marie Blank; Alvira Brands, D.Sc.; James Burr; Jeanette Chamberlain, Ph.D.; Gene Cohen, M.D.; Dorothy Collard; Samuel Keith, M.D.; Judith Lavor, Ben Liptzin, M.D.; Shallie Marshall; Frank Ochberg, M.D.; Milton Shore, Ph.D.; Sam Silverstein, Ph.D.; Thomas Skelley; Nathan Sloate; Elizabeth Smith, Ph.D.; G. Bart Stone, Ph.D.; and Steven S. Sharfstein, M.D.

[7]Membership of the task force included: G. Bart Stone, Ph.D., and William TenHoor, Co-chairmen; Morton Albert, M.D.; Robert Arrindell; Alvira Brands, D.Sc.; Herbert Butler, Ed.D.; Howard Davis, Ph.D.; Earnestine Kiano, Ph.D.; Anne McCuan; Mabel Morgan; Lucy Ozarin, M.D.; Robert Ray; Sam Silverstein; Elizabeth Smith, Ph.D.; Diana Trunnel; and Judith Turner.

S. Sharfstein, Acting Director of the Division of Mental Health Service Programs.[8] This group analyzed the many comments from the field on the draft proposal, synthesized the changes suggested, and prepared detailed Requests for Proposals (RFPs) to be used in competitive contract procurements open to all State mental health agencies.

Consultation With the Field: The Community Support Conferences

While large numbers of NIMH staff shaped the CSP, a far greater number from outside the Institute also made contributions (see appendix A for a list of conference participants). The community support system concept and the basic elements of the implementation strategy were established during a series of small working conferences held from August 1975 to May 1977. The objectives of these conferences were as follows:

1. To assist NIMH in developing guidelines and regulations relative to the new community support and rehabilitation mandates of P.L. 94–63, which amended the Community Mental Health Centers (CHMCs) legislation. (August 1975)
2. To conceptualize and define goals, principles, and terminology to guide the planning of "comprehensive community support systems" for adults with chronically disabling mental health problems. (January 1976)
3. To recommend joint NIMH central office/regional office efforts to develop and improve community support systems, working with State and local agencies. (March 1976)
4. To identify long-range Federal policy issues related to the development of community support systems. (June 1976)
5. To consider policy implications of the GAO deinstitutionalization study with particular emphasis on the role of State mental health agencies vis-a-vis State welfare agencies. (August 1976)
6. To recommend strategies for Federal initiatives to improve community-based living arrangements and services for the mentally ill and disabled. (September 1976)[9]
7. To advise NIMH on the technical assistance and training implications of the community support system concept. (April 1977)
8. To clarify the role of State mental health agencies in developing community support systems. (May 1977)

A notable feature of the conferences was the diverse representation sought at each step in the planning process. Invitees were selected from among nationally known leaders and experts representing State and local mental health and human service agencies, universities, clinicians, researchers, program innovators, legal specialists, citizen and consumer advocates, other Federal agencies, and a number of national organizations involved in mental health and social service issues.[10]

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[8]Membership of the Implementation Group has included: Steven Sharfstein, M.D., Chairman; Morton Albert, M.D.; Michael Benjamin; H. Westley Clark; M.D.; Iris Gelberg; Noel Mazade, Ph.D.; Anne McCuan; Jacque Rosenberg; Ralph Simon, Ph.D.; Elizabeth Smith, Ph.D.; G. Bart Stone, Ph.D.; William TenHoor; and Judith Turner. Marybeth Shinn and Jean Duff, graduate interns during the summer of 1977, made useful contributions to developing the RFPs. The Implementation Group could not function without the dedicated secretarial support of Rita Wiener and Pat Matthews.

[9]Proceedings of this conference are available from the Public Inquiries Section, National Institute of Mental Health, Room 11A–19, 5600 Fishers Lane, Rockville, Md., 20857. The title is "Community Living Arrangements for the Mentally Ill and Disabled: Issues and Options for Public Policy."

[10]Among the national organizations represented at various stages in the conference series were: the National Association of State Mental Health Program Directors; the Mental Health Association; the National Council of Community Mental Health Centers; the International Committee Against Mental Illness; the International Association of

(Continued on next page.)

Development of the Community Support System Concept

At the first conference, convened specifically to assist NIMH in developing guidelines for the community support and rehabilitation aspects of P.L. 94–63, a number of basic policy and programmatic issues emerged that highlighted the need both for improved planning concepts and for more effective service development strategies. An example was the heated debate over the question of whether the new CMHC mandate for "programs of transitional halfway house services" should be limited to halfway houses, per se. Priscilla Allen, the former patient mentioned earlier, Hilary Sandall, a State hospital psychiatrist, and John Beard, director of a pioneering psychosocial rehabilitation agency in New York, were among those advocating a broader interpretation that would include supervised self-help apartments—a view that was later adopted by NIMH. Part of their concern was a recognition that the more disabled patients are often excluded from halfway houses. Although these people may need long-term supportive living arrangements, they do not need long-term hospitalization. Yet "transitional services" alone are also inadequate.

This raised questions as to the appropriate limits of the CMHC role and responsibility regarding the provision of housing opportunities and with respect to the CMHC mandate for "followup care." Should the mandate be interpreted narrowly as referring to clinical mental health aftercare only, or should a broader and more comprehensive "case management" responsibility be assumed? If CMHCs were not to assume case management responsibility, who should do so?

Recognizing the complexity of many of these questions, the Community Support Work Group decided to convene a second working conference in January 1976 designed to develop an idealistic conceptual model of a comprehensive service system for mentally disabled adults. A deliberate decision was made to defer the questions of who should be responsible for implementation and who should pay.[11]

In attempting to articulate their shared perception of an optimal service system, conference participants confronted many value issues.[12] How should planners deal with the conflict between organizing services for the benefit of a disabled population, versus attending to the need of society to maintain order and the desires of service providers to use skills for which they have been trained? What priority should be established in directing limited health and social service resources to victims of the disabling service systems that have prevailed? How will this affect efforts to prevent primary or secondary disabilities among persons just entering the system? To what extent should government assume responsibility for meeting human needs? Can strategies be developed to enhance personal, family, and community responsibility and to minimize reliance on government? Should service planners attempt to impose prevailing social values of independence and productivity on people who seem to prefer a dependent lifestyle? These were a few of the basic questions raised during an intense 2½-day period.

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Psychosocial Rehabilitation Centers; the American Public Welfare Association; the National Conference on Social Welfare; the American Federation of State, Municipal, and County Employees; the Mental Health Law Project; and the American Psychiatric Association. Federal agencies consulted in the process included: the Rehabilitation Services Administration; the Public Services Administration; the Medical Services Administration; the Department of Housing and Urban Development; and the Social Security Administration. See appendix A for a list of conference participants.

[11]Robert J. Howell, Ph.D., of Brigham Young University, and E. B. Whitten, a senior statesman from the rehabilitation field, provided valuable consultation concerning the advisability of clarifying goals and concepts before developing implementation initiatives. Thomas F.A. Plaut, Ph.D., Deputy Director of NIMH also advocated this course.

[12]Reading material on philosophical and conceptual issues, including articles by Wolf Wolfensberger (1970), David Mechanic (1978), and Gerald Caplan (1974), provided valuable stimuli for these discussions, as did a keynote speech by Wolfensberger (1976) entitled "Values and Ideology in Human Services Management: A Perspective From the Field of Mental Retardation."

Despite the differing positions taken by conference participants on these issues, there was clear agreement on the need for a Federal initiative focusing on the severely mentally disabled adult. In addition, the conference succeeded in generating substantive material and considerable consensus on the major topics discussed: functional characteristics of severely mentally disabled adults; their basic and special needs; the functions that an organized community support system should perform; the conditions necessary for constituting a system; and the principles that should guide reform efforts.

An extensive conference summary drafted by E. B. Whitten and Valerie Bradley was sent to all participants for comment, and was later revised in the form of a short working paper that was even more widely circulated (Turner 1977). This working paper, as subsequently revised based on input from the field, now provides guidelines for CSP contracts (Community Support Section RFPs 1977).

Development of the CSP Implementation Strategy

The implementation strategy for CSP also depended on participatory planning. The first two conferences identified many implementation issues, including the need to clarify the role and responsibilities of Federal, State, and local agencies and of mental health vis-a-vis a wide range of health and human service agencies. The GAO study of deinstitutionalization identified the problems more precisely. Based on the preliminary findings of the GAO report, NIMH continued consultation with the field in seeking solutions. An August 1976 meeting with representatives of State mental health agencies, State welfare agencies, and a former State Medicaid administrator highlighted the confusion of responsibility reflected in State plans and in case management at the local level; the idea of Federal contracts with State agencies for service development was offered as a potential mechanism for solution. A September 1976 conference with even broader representation further developed State contract ideas and provided useful input to the internal NIMH Task Force then working to update the Hospital Improvement and Hospital Staff Development Programs (NIMH Conference Proceedings 1976).

An April 1977 conference focusing on the technical assistance and training implications of the community support system concept proved more useful in designing RFPs for contracts with States. Participants at this conference emphasized that some States have completed considerable planning in this area and are ready for implementation initiatives. This led to a decision by NIMH to provide two types of CSP contracts, a "strategy-development" contract for States with a need for more extensive planning, and a "community support system demonstration and replication" contract that would test different ways to develop community support systems in local demonstration areas.

Definition of a Community Support System

Before the implementation strategy is described in more detail, it will be useful to summarize the major features of the community support system (CSS) concept. NIMH guidelines for the CSP (1977) define a CSS as "a network of caring and responsible people committed to assisting a vulnerable population to meet their needs and develop their potentials without being unnecessarily isolated or excluded from the community" (appendix A, p. 1). It is recognized that this general concept could be adapted to numerous vulnerable populations. At present, however, CSP is limited to one such group.

Components of a Community Support System

CSP guidelines specify that however a particular State or community arranges its services, an adequate system for the severely mentally disabled must fix responsibility and provide staff and resources to perform the following functions:

1. Identification of the target population, whether in hospitals or in the community,

and outreach to offer appropriate services to those willing to participate.

2. Assistance in applying for entitlements.
3. Crisis stabilization services in the least restrictive setting possible, with hospitalization available when other options are insufficient.
4. Psychosocial rehabilitation services, including but not limited to:
   - goal-oriented rehabilitation evaluation;
   - training in community living skills, in the natural setting wherever possible;
   - opportunities to improve employability;
   - appropriate living arrangements in an atmosphere that encourages improvements in functioning;
   - opportunities to develop social skills, interests, and leisure time activities to provide a sense of participation and worth.
5. Supportive services of indefinite duration, including supportive living and working arrangements, and other such services for as long as they are needed.
6. Medical and mental health care.
7. Backup support to families, friends, and community members.
8. Involvement of concerned community members in planning and offering housing or working opportunities.
9. Protection of client rights, both in hospitals and in the community.
10. Case management, to ensure continuous availability of appropriate forms of assistance.

Conditions Necessary for Constituting a System

Assuming that all of the above opportunities and services are available within a given planning area, the following conditions are considered prerequisites for constituting a *system* (CSP RFPs 1977):

1. The comprehensive need of the population at risk must be assessed.
2. There must be legislative, administrative, and financial arrangements to guarantee that appropriate forms of assistance are available to meet these needs.
3. There must be a *core services agency* within the community that is *committed* to helping severely mentally disabled people improve their lives.
4. There must be *a single person (or team)* at the client level *responsible* for remaining in touch with the client on a continuing basis, regardless of how many agencies get involved.

Unique Features of the CSS Model

As planning concept, the CSS model offers certain advantages over frameworks that have guided services to the severely mentally disabled in the past. For example, the traditional concepts of "precare" and "aftercare" have been misleading in their implications that the *real* care happens in the hospital, and inadequate in their lack of systematic attention to the wider array of human services required by the target population. The various components of a CSS deal with the whole range of functions an organized service system should perform for those with major mental disorders—prevention of secondary disabilities among persons just entering the system, rehabilitation, and long-term support for persons whose condition has stabilized or whose functioning may inevitably deteriorate.

In this respect and others, the CSS concept has much in common with the Balanced Service System (BSS) concept now being piloted by the Joint Commission on Accreditation of Hospitals as the basis for accrediting community mental health centers (JCAH 1976).[13] Both concepts

[13]Even in the early phases of developing the CSS concept, the more sophisticated conceptual efforts of the authors of the BSS were noted and used as a stimulus in the planning process. For example, a preliminary draft of BSS functions

(Continued on next page.)

are intended to ensure that priority attention is given to the most severely ill and disabled; both concepts encourage use of the least obtrusive, most normative service methods and settings; and both encourage service planners to enhance natural support systems potentially available in the community.

The major difference between the two concepts is in the scope of the populations included. Whereas the BSS concept relates to *all* mental health target groups divided into 12 subcategories based on age and type of disability, the CSS concept is limited to *one* of these subgroups—the adult mentally ill. Because the CSS concept is limited to a well-defined population, it is possible to incorporate a number of features based on experience and research with this population. Some of these are discussed below.

Recognition of Unique Characteristics of the Population

The planning conferences and NIMH's resulting guidelines highlight a number of functional characteristics of the target group: their difficulty with basic activities of daily living; their recurring problems in meeting such basic needs as those for food, clothing, and shelter; their apparent lack of either motivation or ability to seek help from or sustain rapport with human service workers; their extreme vulnerability to stress; their tendency toward episodes of acting-out behavior that interfere with their own well-being or that of others; and the fact that their illnesses or disabilities are not usually remediable by short-term treatment.

The list of components required in a comprehensive CSS reflects consideration of these characteristics. The CSS model calls for specific attention to such matters as outreach (into the community) and inreach (into the hospital) to ensure that those most in need of service are aware of the kinds of assistance available: help in meeting basic needs for income, living arrangements, work, and socialization; assistance in negotiating the service system; and crisis stabilization services available on the spot, with hospitalization seen as appropriate when other options are insufficient.

The CSS model also reflects specific findings from research. For example, research has indicated that training in the skills of daily living is usually more effective when provided in the real-life settings in which skills will be used (Test and Stein 1976, 1978). Hence the CSS model identifies "in vivo" skills of daily living as a specific subelement of psychosocial rehabilitation services. Similarly, numerous studies have shown that the rehabilitation of the psychiatrically disabled is often a long-term process (Anthony 1978). Hence, the CSS model calls for "supportive services of indefinite duration," including special living arrangements and work opportunities in which clients may remain as long as they require support. (At one of the NIMH conferences, these supports were referred to as the social equivalent of braces, ramps, and wheelchairs. With such supports as semisupervised living arrangements, crisis help, and supportive or part-time work arrangements, many mentally disabled persons can function reasonably well most of the time. Without such help or with the wrong kind of help, they may become almost totally dependent.)

Recognition of the Potential of the Population

The CSS model is an attempt to promote service systems that maximize the potential of mentally disabled persons. It should not be assumed, for example, that the mere existence of such services as halfway houses, community residences, sheltered workshops, or day treatment programs necessarily indicates the presence of a viable CSS. Too often, such agencies

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was provided as background material at NIMH's conceptual conference in January 1976. From this draft, the idea of "service system principles" was adopted as part of the CSS framework. Further cross-fertilization occurred when the CSP draft proposal was circulated to the field in March 1977. Recognizing the compatibility between the two approaches, Donald Miles and John O'Brien, both of whom had participated in developing and implementing the BSS concept, provided valuable assistance in refining CSS components to minimize overlapping service functions.

fail the more seriously disabled in a variety of ways: exclusion of such patients by policy or practice; offering only time-limited "shape up or ship out" programs; doing things for clients that they could be helped to do for themselves; or perpetuating stigma and dependency by offering no alternatives to the patient/client role.

A powerful theme among leaders in psychosocial rehabilitation (and at the community support conferences) is the importance of providing opportunities for mentally disabled persons to be *needed*, to make a real contribution. Another theme is the need to provide choices for clients, rather than assuming, for example, that people regarded as "chronic patients" must be limited to group homes with 24-hour or live-in staff, or work arrangements in a sheltered workshop.[14]

Because of these concerns, the CSS model is intended to encourage further development of the more dynamic and less restrictive approaches that have been successfully demonstrated around the country: rehabilitation clubs in which patients are treated as needed and valued members (Glasscote 1973); semisupervised self-help apartment living programs (Goldmeier 1977); and transitional employment programs in commerce and industry (Beard, Schmidt, and Smith 1963). By providing opportunities for clients to assume normal social roles, these approaches are in sharp contrast to programs—whether institutional or community—that perpetuate a passive "patient" role. In this respect, the CSS model can be seen as calling for a system of *opportunities*, not just a system of *services*. It should also be noted that the CSS model incorporates elements from the medical model, elements from the rehabilitation model, and elements from a social support model. All three of these approaches have relevance; any one of them alone is inadequate to the needs of this population.[15]

Recognition of the Need to Support Families and Communities

Another feature of the CSS model is the explicit emphasis not only on assisting the patients or clients, but also on helping family and community members cope with the presence of mentally disabled persons in their midst. If the CSSs are to develop on a broad scale, the importance of this kind of service cannot be overemphasized. The outcry in many communities against an influx of former patients has clear implications for service planners. Mechanisms must be established to disperse mentally disabled persons and avoid congregating them in numbers greater than the community can readily absorb. Cooperative apartment programs, for example, are promising in this respect. In addition, the mental health system should provide trained staff skilled in counseling family and friends, willing to make crisis visits when problems occur, and able to consult with a broad range of community agencies now encountering large numbers of mentally disabled individuals for the first time.

In the long run, the stigma associated with mental illness may diminish. Public education may be able to contribute toward this goal, although the state of knowledge on how to change attitudes and behavior is primitive. Many of those most experienced with community services to the mentally ill suggest, however, that no amount of information about the nature of mental illness and no amount of exhortation about the need for "community acceptance" can substitute for trained staff available to provide help when and where it is needed. Although these functions are implied in the community mental health concept of "consultation and education," the focus of such services relative to the severely disabled has not been clearly articulated or fully developed.

[14]For a consumer perspective on these issues, see Ronald Peterson's (1978) "What Are the Needs of Chronic Mental Patients?" Peterson speaks from experience, having spent several years as a psychiatric inpatient before going through the rehabilitation program at Fountain House in New York and later joining the staff there.

[15]For an up-to-date literature review supporting this thesis as it relates to schizophrenia, see Gunderson (1977).

Acknowledgment That the Community Can Provide Support

While recognizing the need of community members for assistance *from* the organized service system, the CSS concept also recognizes the capacity of the community to *provide* support to mentally disabled persons. CSS principles include specific attention to encouraging mutual and self-help, maximizing natural support systems, and avoiding the tendency to do things for clients that they or their families and friends could do on their own (CSP RFP 1977).

Whether or not community support planners can overcome community resistance, they are encouraged to mobilize community caring. The involvement of concerned community members is seen as an essential CSS component. Methods of involvement may include such activities as helping in program planning, serving as volunteers, or helping to make jobs or housing opportunities available. An example of positive community involvement is the way in which Fountain House and other agencies work with commerce and industry to provide transitional employment opportunities. Their experience is that employers are often glad to help—particularly when the agency provides all the backup necessary to minimize risk (Beard 1977).

The CSS Model Is Flexible

Despite its high degree of specificity, the CSS model is flexible because it is *function*-specific, rather than *facility*-specific. The assumption is deliberately avoided that a particular type of service can be performed only by a particular class of facility or a certain type of service setting. This feature is intended to encourage local communities to make effective use of facilities and resources they may have in place—e.g., mental hospitals, community mental health centers, psychosocial rehabilitation agencies, community residences, public and private service agencies, and programs designed for the general population. The CSS planning tasks are to identify (1) all of the ways in which the 10 components of a CSS are being or could be provided, and (2) the steps required to fill gaps, improve coordination, or assure availability of the needed services to larger numbers of the target population.

As an example of this flexibility, the CSS model avoids the planning dichotomy between "institutions" and "community alternatives." A theme in the NIMH conferences was the need for an integrated system making appropriate use of a variety of facilities, including hospitals when necessary. Hence the mental hospital is seen as *part of* a CSS, potentially serving a variety of functions depending on resources in the area.

The model is also flexible in approaching the question of how the broad range of services should be coordinated at the community level. While it calls for a "core service agency" that will assume a leadership and advocacy role on behalf of the target population in each planning area, the model leaves open the question of what type of agency is best suited to this role. This question can best be decided at State and local levels, where existing facilities, resources, interests, and initiatives can be taken into account. In some instances, the mental hospital may be in the most obvious and advantageous position to assume this role, re-deploying staff into the community with the patients. In other instances, it may be a community mental healh center, a free-standing agency, a transitional services corporation, or a rehabilitation center.

Features of the CSP Implementation Strategy

The broad range of services required in a CSS and our understanding of problems that have impeded the availability of such services in the past have led to the development of a complex implementation strategy involving three levels of government and a wide range of health, mental health, and human service agencies at each level. The major elements of the strategy include the following: NIMH contracts with State mental health agencies for two types of pilot projects; assumption by NIMH of an advocacy role with other Federal agencies who share responsibility for serving the mentally disabled

in the community; convening three times annually of a "learning community" comprised of leadership from Federal, State, and local agencies involved in CSP projects; and a national evaluation of CSP projects to clarify implications for policy and practice.

An Intergovernmental Partnership

A central feature of the CSP is the use of two types of contracts between NIMH and State mental health agencies.[16] One type of contract is a CSS strategy development contract; the second is a demonstration and replication contract. Both are designed to examine in different ways the problems of financing, involvement of "mainstream" agencies, community organization and advocacy, and leadership. Both types of contracts call for the establishment within the State mental health agency of a focal person or unit responsible for promoting local community support efforts. Both types call for leadership by the State mental health agency in fostering a participatory planning process that clarifies resource needs and that mobilizes diverse groups within the State to work together to improve services to mentally disabled adults. An end product of both types of contracts is a 3-year statewide action plan for developing CSSs. This plan must include specific and widely agreed-upon goals, objectives, action steps, timetables, resource requirements, incentives, and sanctions. Both types of contracts are awarded for an initial 1-year period with the expectation that they will be extended (based on performance) for an additional 2 to 3 years.

Only State mental health agencies are eligible to apply for CSP contracts; local agencies become involved by subcontracting with the State agency. This approach was chosen for several reasons. State agencies have a history of caring for and an ongoing statutory commitment to the mentally disabled. They control the major source of State funding for services to this population. They are in a position to promote coordination between hospital and community programs for the mentally ill. In addition, such agencies are in a position to reach out to other health and human service agencies to assure that concerns of the mentally disabled are considered in allocating resources. Since directions and priorities for a number of key programs are determined at the State level, there is a clear need for working through the States in developing CSSs.

The contracting mechanism was chosen instead of a granting mechanism because it provides for a close working partnership between NIMH and the States—a desirable goal in implementing a pilot program. The contracting mechanism has the additional advantage of facilitating the development of a national CSP evaluation to examine certain issues across projects.

Strategy Development Contracts

Strategy development proposals were invited from all States regardless of their level of development. In effect, these contracts call for a new type of State planning effort focusing on meeting the comprehensive needs of a specific population through a broad range of health, mental health, and human service programs. To date, strategy development contracts have been awarded to Alabama, Arizona, Georgia, Maine, Maryland, New Jersey, Ohio, and Oregon.

While the goals of these projects are identical, structures and mechanisms to pursue the goals vary from one State to another. In Oregon, for example, the strategy for involving mainstream agency participation is provided by New trol in a steering committee at the Department of Human Resources level. The CSP unit, though placed in the Mental Health Services Division, staffs the steering committee. An advisory group, borrowing in part from an existing committee in the division and including, in addition, citizen and consumer advocates, is being created

[16]The National Association of State Mental Health Program Directors (1978) recently released a statement to the President's Commission on Mental Health advocating an intergovernmental partnership in services to *all* mentally disabled groups, through performance contracts between Federal and State government and between State and local government.

as well. A third structure is a technical advisory committee consisting of direct service mental health providers and academicians.

A more typical approach to developing mainstream agency participation is provided by New Jersey's attempt to obtain gubernatorial commitment for an interagency coordinating council to address community support needs. Ohio already has such a structure and is working to develop a uniform services classification language with the Title XX and Community and Economic Development agencies. If successful, this should greatly facilitate the development and integration of services.

New Jersey already has a comparatively long history of coordination between mental health and human service agencies on behalf of the mentally ill. Its State agency has ongoing activities involving extensive use of the Comprehensive Employment and Training Act, Title XX, vocational rehabilitation, and HUD programs. Their experience in this area should assist other States beginning this process.

Since the CSP project's initiation in Georgia, CSP activities have been highlighted as one of four priorities by the Division of Mental Health and Mental Retardation; the position of the Division's Supportive Living Coordinator has been upgraded to strengthen that program; and discretionary State funds under Section 314(d) of the Public Health Service Act have been earmarked for CSP development. Though these individual accomplishments are modest, as a group they reflect the gradual realignment of priorities necessary to achieve CSP goals.

Demonstration and Replication Contracts

The demonstration and replication contracts were designed for States that have clarified some elements of their program development strategy and that also have one or more local areas capable of demonstrating an exemplary CSS. Contract activities include upgrading and documenting the effectiveness of the local CSS model, analyzing the manpower and cost implications, and developing a 3-year action plan (here referred to as a "replication strategy") for instituting similar programs on a statewide basis. To date, demonstration contracts have been awarded to Colorado, Florida, Massachusetts, Michigan, Minnesota, Missouri, Montana, New York, South Dakota, and Texas. A proposal from California is under active consideration and negotiations are in a preliminary stage with the District of Columbia concerning the possibility for a special project there.

A particularly gratifying aspect of the demonstration projects is the variety of local approaches being tested. The RFPs required the States to select local demonstration areas where many CSS elements were in place to a significant degree. Within each demonstration area, a "core service agency" must be designated to assume the leadership for improving services for the client group. As noted earlier, the type of agency to perform this function was deliberately left flexible, allowing planners to build on the resources, initiative, and commitment that exist in various communities within the State.

In Florida, a free-standing "psychosocial rehabilitation center" known as Fellowship House serves as the core of the local program. Fellowship House programs now in place include a community-based rehabilitation club on the New York Fountain House model, a variety of social and prevocational opportunities, an array of living arrangements including supervised apartments, and a transitional employment program providing job opportunities in commerce and industry with intensive backup from Fellowship House staff (Beard, Schmidt, and Smith 1963). This project illustrates, among other things, the important role that vocational rehabilitation can play. The State vocational rehabilitation agency is a major funding source for Fellowship House Programs. The NIMH contract complements a related project funded through the Federal Rehabilitation Services Administration (RSA). NIMH and RSA staff members collaborated in reviewing both projects at the Federal level to avoid duplication of effort.

Missouri's demonstration area is the city and county of St. Louis, where "Places for People, Inc." will take the lead. This is a private nonprofit agency developed on the initiative of

Hilary Sandall, a psychiatrist from the St. Louis State Hospital. Services in place include extensive followup of discharged patients, use of former hospital employees to provide community living training and other assistance, a large cooperative apartment program, a transitional employment program, and a community rehabilitation club (Sandall et al. 1975).

New York selected three demonstration areas, one of which illustrates how an extensive community program can be developed through the redeployment of hospital staff and resources. At the Harlem Valley Psychiatric Center, program elements in place include a nonprofit corporation called Search for Change that works on housing, an extensive family care program, a transitional employment program, a sheltered workshop, and 10 satellite shops. The demonstration plan will include the following: developing legal advocacy, developing foster care, improving transportation, and intensifying socialization and community involvement programs. Other core agencies in New York's project are the Hutchings Psychiatric Center and the Schenectady Shared Services Program, formed through the collaboration of a State hospital and a CMHC.

Another local model is provided by the Southwest Denver Community Mental Health Center, serving as the core service agency for Colorado's demonstration project. In place is a nationally recognized community crisis program that keeps inpatient hospitalization to a minimum (Polak and Kirby 1976; Polak 1978). Agency staff members provide intensive backup to foster home providers and other community care givers. Project goals include developing a HUD-supported apartment program in collaboration with the State mental health agency; developing a special team to work with the chronically disabled in the community; developing a social club and drop-in center; developing a program of training in community living skills; and other activities to fill existing gaps.

All of the demonstration projects also involve State level program development and interagency work. In Florida, the State office of vocational rehabilitation has agreed to assign two people to help the mental health agency in manpower and replication planning activities. In Michigan, needs assessment and replication planning will be done through the regional structure in the department. The State leadership role has been most strongly spelled out in New York, where the CSS concept has been adopted as the basic framework for the first phase of a recently announced 5-year plan (New York State Five-Year Plan 1978). During the first year of the plan, a $12 million State budget for CSS development has been requested—more than three times the NIMH budget for the first year of national CSP activities!

Federal Interagency Collaboration

The basic administrative and funding strategy of CSP is to use very limited NIMH dollars to make what Brown (1977) has referred to as "an investment in an investment." CSP projects are intended to stimulate better use of two major types of funding for services to the severely mentally disabled: (1) State mental health system resources, and (2) the resources of other "mainstream" Federal and State programs such as vocational rehabilitation, Medicaid, Supplemental Security Income, Title XX (social services), employment, and housing. To pave the way for State efforts to work with other agencies, NIMH is undertaking an advocacy role at the Federal level (within the constraints of a very small staff currently assigned to the CSP unit). To date, efforts have been focused principally on working with RSA and HUD. A formal cooperative agreement has been developed between NIMH and RSA, calling for joint planning and program implementation in services, research, and training. Advocacy within HUD has resulted in the clarification of eligibility of the mentally ill for a variety of types of Federal housing assistance, and most significantly in an $18 million HUD demonstration program targeted toward the chronically mentally ill. A technical assistance manual on how mental health providers can gain access to Federal housing programs has been prepared through an NIMH contract and is now available (NIMH/HEW 1978).

In addition to finding new opportunities in existing Federal programs, NIMH is interested in identifying obstacles to effective interagency collaboration. CSP pilot projects will provide a framework for documenting such obstacles at the client, local, and State levels. A close tie-in between CSP experience and NIMH's ongoing policy development process is being encouraged. For example, CSP project representatives have been consulted in NIMH's effort to respond to policy options being considered by a recently initiated HEW Task Force on Deinstitutionalization, under the leadership of the Assistant Secretary for Planning and Evaluation. As processes of this kind continue and expand, it should be possible over 2 to 3 years for NIMH to develop a comprehensive set of policy recommendations. Based on documented experiences in 19 or more States, these recommendations, if implemented, should foster needed improvements in services for the mentally disabled.

"Learning Community" Conferences

Another important element in the CSP strategy is the development of a "learning community" and communications network among leaders associated with CSP activities at Federal, State, and local levels.[17] The idea of a "learning community" stems from NIMH recognition that the development of CSSs on a broad scale will be an extremely complex process—clinically, legally, administratively, financially and otherwise. Long-range success in this effort will require a continuous posture of learning and problem solving among those committed to the tasks involved. In addition, as we encounter numerous inevitable setbacks and resistances, there will be an increasing need for individual State and local agencies to see their efforts in the context of a larger social reform process. Through the learning community, individual "change agents" from around the country can give and receive both information and moral support. Finally, the interaction of key individuals in a learning community milieu should foster the development of long-range strategies that take into account realities and problems at all levels.

The first learning community conference was held in late January 1978.[18] Proceedings of the conference will be available from NIMH by the fall of 1978. In addition to clarifying NIMH expectations of the projects and providing an opportunity for program participants to form working relationships among themselves and with Federal staff, the conference was designed to present a large amount of information basic to the CSP. This included an overview of the state of the art by Leonard Stein, a workshop on crisis stabilization in the community by Mary Ann Test and Michael Kirby, a workshop on psychosocial rehabilitation by John Beard and others from Fountain House, presentations by Federal agency staff members on how their programs can assist the mentally disabled, and information from the HEW Deinstitutionalization Task Force, the President's Commission on Mental Health, and NIMH on the current Federal policy context.

An interesting feature of the learning community approach is the flexibility it affords for various participants to provide input from their areas of strength. For example, NIMH staff members interpreted the intent of the RFP tasks and presented certain aspects of the Federal policy-making process. NIMH adopted the stance of consultee by obtaining advice from

[17]The "learning community" was developed through a time-limited CSP Technical Assistance and Training Work Group, chaired by G. Bart Stone, Ph.D. The group included: Ralph Simon, Ph.D., and Elizabeth Smith, Ph.D., of the Division of Manpower and Training; Morton Albert, M.D., Jean Duff, Anne McCuan, Marybeth Shinn, William Ten-Hoor, and Judith Turner of the Division of Mental Health Service Programs. It was Marybeth Shinn who had primary responsibility for synthesizing the ideas of the group in written form. Collaboration between the CSP unit and the State Manpower Development Program of NIMH's Division of Manpower and Training has been part of the CSP planning process since the initial Hospital Improvement and Hospital Staff Development Task Forces were established.

[18]Coordinators and key planners of the conference were Michael Benjamin and Jacque Rosenberg of the CSP staff. The design of the conference was developed by the CSP Implementation Group. Noel Mazade of the NIMH Staff College and Elizabeth Smith, Ph.D., of the Division of Manpower and Training were valuable consultants.

project personnel on Federal policy options, on how to improve the CSS conceptual framework, and other such topics. Project staff members were frequently in the role of consultants to each other on such topics as approaches to statewide participatory planning. In future meetings of the learning community, it is anticipated that project representatives will have an even greater role in planning the agenda and providing leadership in problem solving.

Evaluating the Community Support Program

Because of the pilot nature of the program, it is vital to document experiences of the projects in a form that will be useful in improving policy or practice at Federal, State, and local levels. For this reason, in addition to requiring that local demonstration projects conduct an internal evaluation, CSP contracts require all projects to provide data for a national evaluation. In planning an overall evaluation strategy, NIMH has identified several areas of inquiry that would be useful from a national perspective. Some of these are discussed below.

What Is the Extent of Need for Community Support Systems?

In order to reconsider Federal policy and its impact on the mentally disabled, more systematic information is needed on the total numbers of mentally disabled adults, their clinical and demographic characteristics, their current locus of services, the types of services they are now receiving, their quality of life and level of adjustment, the extent to which they are "inappropriately placed" either in hospitals or in the community, and the nature and extent of unmet service needs. Statewide needs assessment activities will provide a basis for organizing available information and identifying gaps in knowledge in this area.

What Are the Effects of the Community Support Program?

The ultimate goal of CSP is to assure that clients have access to relevant services—continuing mental health care, a place to go or someone to call in times of crisis, decent living arrangements with as much independence as possible, a chance to work or participate in other meaningful activities, and opportunities to develop life satisfactions. It would be desirable to document changes in local service systems over time to see whether new opportunities are being created and whether available facilities and resources are gradually being used more appropriately by CSS clients. These are complicated questions, however. We cannot look for much short-term change in local demonstration areas because most of them were comparatively well-developed when they entered the program. Improvements on a statewide basis will take time and will be affected by many factors, of which the CSP project will be only one. Such a project alone cannot be expected to have measurable impact in the near term. Compared to most State mental health system budgets, the CSP project is a drop in the bucket. Cause and effect relationships between CSP and systems change will be hard to document.

Nonetheless, we believe CSP provides a useful stimulus in the right direction. Instead of attempting to document systems change over time, it may be more feasible to evaluate intermediate indicators of State and local leadership in CSS development. Such indicators include clarification of roles, responsibilities, and resource commitments of key State agencies working with the target population, identification of new resources or re-allocation of existing resources to CSS services, support for CSS from key groups in the State, and accomplishments in implementing CSS strategies.

What Are the Benefits of Community Support Systems?

It would be desirable—although methodologically complex and expensive—to develop outcome data demonstrating ultimate benefits to clients, families, communities, and staff working with the clients. In light of the complexities, it will be a formidable challenge to avoid inap-

propriate outcome criteria, premature data collection, and misleading analyses.

From a system perspective, it may be desirable to demonstrate that the CSS approach has advantages over the more traditional approach in which agencies carry out their missions while their responsibilities for meeting the comprehensive needs of the target population are unclear. This would require comparisons of CSS demonstration areas with areas in which a CSS effort has not been mounted. Some States are considering comparison areas, but no final decisions have been made. It would also be desirable to collect information on family and community impact. Such benefits as reduction in family burden and reduction in distress of citizen groups objecting to the high visibility of mentally disabled persons in their neighborhoods should result from the CSS. Though the level of effort required to study these issues is beyond the scope of existing projects, we hope that these concerns can be examined in one or more special studies.

At the client level, we do not expect dramatic changes in client functioning, but we are aware of the importance of documenting what happens as a basis for advancing knowledge of how to serve this population. It would also be desirable to include quality of life and client satisfaction in the evaluation. Since the CSS model assumes that individual clients need different numbers and intensities of the 10 CSS components at different times, "it is important . . . that outcome measures be selected for each client on the basis of the unique combination of services the person is obtaining, rather than assessing all CSP participants on uniform outcome criteria" (Schulberg 1978). To do this kind of evaluation well will be expensive; to do it in a superficial way will be misleading.

What Strategies Are Effective in Developing Community Support Systems?

Because of the necessity for States and communities to address the needs of the target population more effectively, it will be important to generate meaningful information on what worked, what didn't work, and why. Other States and communities will need "how to" information. Specifically, the evaluation in this area would be designed to identify the range of strategies used by the 19 States in planning, organizing, funding, and monitoring services to this population, and to determine the pros and cons of different approaches under different circumstances. In addition, it would be valuable to examine factors associated with positive changes resulting from the CSS effort and to document resistances and obstacles encountered. Consideration is now being given to developing a special project to study the process of CSS development along these parameters.

What Will It Cost to Provide Community Support Systems on a Broad Scale, and Who Will Pay?

In view of the large number of competing claims on health and human service dollars, the question of costs is vital to the future of the CSS approach. Many of those who have consulted with NIMH in planning the CSP believe that the total resources now being spent on this population would, if better used, be sufficient to support vastly improved systems. Many of the clients now living in semicustodial boarding homes without adequate services could live in self-help apartments linked to rehabilitative programs. The costs of housing would be approximately the same. Some of the staff already employed in the system could serve in different functions. Instead of doing one-to-one therapy, for example, they might help clients organize mutual support groups. Or instead of providing day "activity" programs on traditional models, they could develop crisis teams, organize or provide in vivo training of clients in community living skills, or develop other needed alternatives. These alternatives illustrate the thesis that CSSs are *not necessarily* more costly than more traditional approaches. Although at least one cost study comparing a comprehensive "community treatment program" with traditional hospitalization and aftercare has been reported (Weisbrod, Test, and Stein 1976), we

lack extensive data to support this thesis. And, if in fact the costs are much greater than expected, it is important to recognize this early. Thus we need to establish a data base on the total costs of the CSS in several local demonstration areas. These data could be examined to determine the extent to which the systems can be improved through reallocation of existing resources and the extent to which new resources are needed. It will also be possible to project the proportionate costs of alternative organizational and funding strategies to different levels of government and private sources and among different agencies. In addition, it will be important to examine indirect costs of providing or not providing services (e.g., family burden, costs to law enforcement and welfare agencies, and loss of employment).

Because of the many agencies involved in any CSS, the cost questions are complex. We hope that one or more special studies can be mounted in this area.

What Is the Feasibility of Developing Comprehensive Community Support Systems on a Broad Scale?

The CSP is a pilot program in the sense that we are trying out a particular conceptual model and a particular program development strategy. We recognize that both the model and the strategy are likely to require modification in light of experience and subsequent developments in the field. The evaluation should be designed to generate information that will help keep the program on target.

Philosophically and conceptually, the CSS model is based in part on experience and research from selected local programs that have proved to be reasonably effective with at least some CSP clients. These programs include, to name a few, the Program of Assertive Community Treatment in Wisconsin (Test and Stein 1978); the St. Louis Community Homes Program (Sandall, Hawley, and Gordon 1975); the Lodge concept (Fairweather et al. 1969); community crisis approaches such as Soteria House (Mosher, Menn, and Matthews 1975); the Southwest Denver program (Polak and Kirby 1976); and psychosocial rehabilitation approaches demonstrated by Fountain House, Horizon House, and other similar agencies (Glasscote 1971). None of these programs in itself is a total CSS as defined by NIMH; however, each offers effective approaches to providing several essential system components. Some of these programs have been extensively researched; others less so. In addition to research, the CSS model reflects conscious attention to values made explicit in the planning conferences.

The CSP attempts to use a very small amount of Federal money to stimulate the development of a full array of such programs within the context of a planned accountable system. We are aware, however, that the "model" programs that have influenced our goals are all exceptional in one way or another. Some have developed in a research mode. All involve exceptionally talented and committed leadership. Developing similar programs around the country will require a number of ingredients: committed leadership at all levels, mobilization of citizen and community support, willingness of professional staff to work in new and unfamiliar roles and settings (some perhaps more taxing and less glamorous than traditional roles), ability of administrators and legislators to reallocate resources, and many other factors. The early phase of the program will tell us much about the feasibility of establishing and maintaining such programs on a broad scale.

Current Status of the Evaluation

It may be noted that our comments about an evaluation strategy are tentative, and for good reason. Resources for this effort are in short supply, and only the most obvious and basic steps have so far been taken.[19] Each project is design-

[19]Jean Duff, a graduate intern during the summer and fall of 1977, assisted CSP staff in developing initial evaluation issues. Her efforts were supplemented by short-term consultation from Andrew Gentile, Ph.D., who helped CSP staff operationalize the CSS components. Most recently, Ben Dean has assumed staff responsibility for coordinating

(Continued on next page.)

ing an internal evaluation plan. In addition, NIMH has convened an initial meeting of evaluators from all of the projects to plan for comparability and uniformity of certain key data elements across projects. A draft instrument has been prepared to document the characteristics of clients being served in local demonstration areas, their levels of adjustment, and the types and intensity of services provided to them. Tentative plans are to collect such data at scheduled intervals on a cross-section of clients being served. There are also plans to follow cohorts of clients over time. Project staff from the State program evaluation units in New York, Michigan, and from the local level in Colorado have been particularly helpful in planning to date.

Preliminary planning is also underway to promote some degree of comparability across projects on the "macro" picture of the system. An operational definition of the CSS population to be used by all statewide strategy projects is being developed. Preliminary discussions have identified the need for a method to organize information from State resource inventories by cross-referencing the available facilities and services with CSS components.

Before finalizing the allocation of resources for various aspects of an overall evaluation strategy, we have recently become aware of the need for an impact model that spells out our assumptions and objectives in operational and measurable terms. This is one of the key recommendations of a consultant, Herbert Schulberg, who was engaged by NIMH to provide an overview of evaluation issues. According to Schulberg (1978), "the CSP format, i.e., broad-scaled, multi-level interventions designed to alter the structure of care-giving systems and the course of people's lives, is exceedingly difficult to evaluate with any degree of precision." Nonetheless, he notes that "rarely can administrators and evaluators collaborate so early in a program's development." The evaluation of the CSP provides an opportunity to use evaluative information "to influence a new programmatic thrust whose potential significance far exceeds the activities undertaken by the initially funded pilot projects." Thus he sees the CSP as "a unique opportunity as well as a challenge" for program evaluators. Whether sufficient staff to coordinate evaluation activities and funds to support them will be allocated in time to maximize this opportunity remains to be seen.

Conclusion

The CSP is a pilot approach in the sense that we are committed to examining concepts and strategies on a continuing basis and to modifying either or both in light of new knowledge and experience. We wish to avoid becoming what Campbell (1975) has referred to as "trapped administrators [who] have so committed themselves in advance to the efficacy of the reform that they cannot afford honest evaluation." Instead, we see ourselves as "experimental administrators [justifying] the reform on the basis of the *importance of the problem*, and *not the certainty of the answer*" (Italics ours). This stance involves a commitment to testing many potential solutions if the first one tried fails.

At the same time, however, it seems clear that we cannot afford to approach the situation in a purely scientific and experimental way, suspending major decisions until all the data are in. Reliance on hospitals to provide *long-term* care for the mentally disabled is not currently a viable option *except* for a small percentage of profoundly disabled individuals. Pressures on the system and the consequences of further delay in initiating action to minimize unnecessary human suffering are such that im-

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the evaluation plan, with support from Mabel Morgan. An informal work group has been assembled, consisting of William TenHoor, Judith Turner, Richard Woy, Ph.D., Charles Windle, Ph.D., Samuel Keith, M.D., Loren Mosher, M.D., and representatives from CSP projects. A working paper on the overall evaluation strategy by Herbert Schulberg, Ph.D., has proved helpful. In addition, extensive consultation and assistance have been provided by Donald Lund, Ph.D., Walter Furman, Ph.D., and Anne Nelson of the New York State Department of Mental Hygiene; by Gail Barton, M.D., and Richard Vaughn, Ph.D., of the Michigan Department of Mental Health; and by Michael Kirby, Ph.D., and Suzanne French of the Denver CMHC. Without the willingness and expertise of these project representatives, little progress could have been made.

mediate steps are required at each level. While many elements of a workable approach remain to be developed, it is clearly incumbent on the mental health system to provide conceptual and programmatic leadership in meeting the needs of people with identifiable psychiatric illnesses and disabilities. The CSP offers a framework within which such leadership can be provided. Ultimately, planning and program development efforts of this kind should occur in every State and community—with or without special financial support from NIMH.[20]

We also believe that all initiatives of this kind should be approached as "pilots." It is not unusual for well-intended reform efforts to result in negative and unforeseen consequences that highlight the need for the next wave of reform. We hope that through making assumptions explicit and through examining experience and findings in formal and informal ways, it will be possible to maximize learning from the program. This learning must then be promptly translated into practical actions that benefit human service workers, clients, and communities in coping with mental disorder.

Summary

NIMH plans for a pilot program to address current service delivery problems affecting the adult mentally disabled in an era of deinstitutionalization are described. Inadequacies in existing services as seen by the press, professionals, a consumer, and Congressional investigators are discussed. Reference is made to legal and judicial pressures on the service system that have necessitated a more concerted approach to serving mentally disabled people in the least restrictive setting. During the past 4 years, NIMH has attempted to provide leadership in seeking needed improvements, and sought to develop a consensus from representative individuals and groups about goals of a reform effort and strategies that might be tested. Two outcomes of this participatory planning process are presented: (1) a reconceptualization of the service elements required by the target population, and (2) the "community support system" model as it is reflected in the NIMH Community Support Program, a pilot strategy for stimulating change. Interagency and intergovernmental aspects of the pilot program, designed to provide a framework within which improvements can be developed and evaluated, are discussed. Key program evaluation issues, tentative NIMH plans for an evaluation strategy, and methodological problems are noted.

[20]The President's Commission on Mental Health (PCMH 1978) has recently released a report calling for the establishment of a nationwide program of performance contracts with State mental health agencies to improve the care of the chronically mentally ill with recommended funding levels of $50 million per year. It is expected that implementation plans will build on experience from CSP pilot projects.

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appendix a

Participants in NIMH Working Conferences on Community Support Systems

From August 1975 to April 1977, NIMH convened eight working conferences to assist the Division of Mental Health Service Programs (DMHSP) design policies and programs to improve opportunities for adults with serious mental disabilities. Dates and goals of each conference are described on page 327 of this article. The following persons participated in one or more of these conferences. (The numbers listed after each person's name indicate the conference(s) by number in which she or he participated.)

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Providing a forum for a lively exchange of ideas ranks high among the *Schizophrenia Bulletin's* objectives. In the section, **At Issue,** readers are asked to comment on specific controversial subjects that merit wide discussion. But remarks need not be confined to the issues we have identified. **At Issue** is open to any schizophrenia-related topic that needs airing. It is a place for readers to discuss articles that appear in the *Bulletin* or elsewhere in the professional literature, to report informally on experiences in the clinic, laboratory, or community, and to share ideas—including those that might seem to be radical notions. We welcome all comments.—*The Editors.*

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